

Association Between Palliative Care and Death at Home in Adults With Heart Failure

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Background—Palliative care is associated with improved symptom control and quality of life in people with heart failure. There is conflicting evidence as to whether it is associated with a greater likelihood of death at home in this population. The objective of this study was to describe the delivery of newly initiated palliative care services in adults who die with heart failure and measure the association between receipt of palliative care and death at home compared with those who did not receive palliative care.

Methods and Results—We performed a population-based cohort study using linked health administrative data in Ontario, Canada of 74 986 community-dwelling adults with heart failure who died between 2010 and 2015. Seventy-five percent of community-dwelling adults with heart failure died in a hospital. Patients who received any palliative care were twice as likely to die at home compared with those who did not receive it (adjusted odds ratio 2.12 [95% CI, 2.03–2.20]; $P<0.01$). Delivery of home-based palliative care had a higher association with death at home (adjusted odds ratio 11.88 [95% CI, 9.34–15.11]; $P<0.01$), as did delivery during transitions of care between inpatient and outpatient care settings (adjusted odds ratio 8.12 [95% CI, 6.41–10.27]; $P<0.01$). Palliative care was most commonly initiated late in the course of a person's disease (≤ 30 days before death, 45.2% of subjects) and led by nonspecialist palliative care physicians 61% of the time.

Conclusions—Most adults with heart failure die in a hospital. Providing palliative care near the end-of-life was associated with an increased likelihood of dying at home. These findings suggest that scaling existing palliative care programs to increase access may improve end-of-life care in people dying with chronic noncancer illness. (*J Am Heart Assoc.* 2020;9:e013844. DOI: 10.1161/JAHA.119.013844.)

Key Words: chronic disease • delivery of health care • heart failure • hospitalization • palliative care

Heart failure (HF) is a leading cause of healthcare use and expenditure.¹ Annually, there are over 1 million visits to the emergency department and more than 4 million hospital admissions attributable to HF in North America.^{2,3} Despite advances in cardiovascular care, the median 5-year survival for hospitalized patients with HF is only 25%.⁴ Up to 30% of people die within 1 year following hospitalization for HF,⁵ and the median time to death following admission to a hospital for HF is 2.4 years.⁶ One in 5 adults with HF are readmitted to the hospital within 30 days;⁷ 50% are rehospitalized for

cardiovascular causes within 1 year, and 30% of these admissions are for HF specifically.⁵ These repeated hospitalizations near the end of life have a negative effect on quality of life.⁸ In light of this evidence new paradigms are needed to deliver high-quality end-of-life care for people with HF.

Palliative care focuses on the care of people who are suffering from serious illness with a goal of improving the quality of life for them and their caregivers.⁹ Cardiovascular societies recommend the integration of palliative care early in the course of a person's disease to improve symptoms, pain,

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Accompanying Data S1 and Tables S1 through S4 are available at <https://www.ahajournals.org/doi/suppl/10.1161/JAHA.119.013844>

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Clinical Perspective

What Is New?

- This cohort study of 74 986 community-dwelling adults who died with heart failure found that 75.4% died in a hospital and 47.1% received palliative care.
- Palliative care often started ≤ 30 days before death and was predominantly delivered by generalist physicians during transitions of care across different settings.
- Initiation of palliative care was associated with a more than 2-fold increase in the probability of death at home compared with those who did not receive palliative care (adjusted odds ratio 2.12 [95% CI, 2.03–2.20]; $P < 0.01$).

What Are the Clinical Implications?

- A significant gap exists in access to high-quality end-of-life care for adults with heart failure.
- Current models of palliative care delivery are associated with death at home.
- These findings suggest that scaling existing palliative care programs to increase access may improve end-of-life care in people dying with chronic noncancer illness.

and quality of life instead of at the end of life.^{10–12} Although palliative care is associated with improved quality of life and reduced symptom burden in people with HF, there is conflicting evidence as to whether palliative care is associated with a reduction in overall healthcare utilization or an increased likelihood of death at home.^{9,11,13–18} Only half of the published studies demonstrated an association between the receipt of palliative care and death at home.¹⁸ Although the evidence for patient-reported preferences on location of death in patients with HF is less well known than for those with cancer, 40% of people with serious illness report that they value the health services available to care for them in their home,¹⁹ and up to 87% of people prefer to die at home.^{20,21} Death at home has been identified as a quality indicator for the delivery of palliative care.^{22,23}

The evidence for palliative care is presently skewed toward patients with cancer, which may limit its applicability to those with noncancer illness.^{9,11} Current models for the delivery of palliative care may need to be redesigned to address the often unpredictable clinical course for patients with chronic noncancer illness such as HF in comparison to those with cancer.²⁴ Few studies have described population-based end-of-life care and the delivery of palliative services care in people dying with HF.^{25–27} The objective of this study was to describe healthcare use near the end of life in adults with HF and to measure the association between receipt of newly initiated palliative care and death at home.

Methods

Access to Data

The data set from this study is held securely in coded form at ICES (formerly known as the Institute for Clinical Evaluative Sciences). Although data-sharing agreements prohibit ICES from making the data set publicly available, access may be granted to those who meet prespecified criteria for confidential access, available at www.ices.on.ca/DAS. The full data set creation plan and underlying analytic code are available from the authors on request, with the understanding that the programs may rely on coding templates or macros that are unique to ICES.

Study Design, Setting, and Data Sources

We conducted a population-based cohort study in Ontario, Canada, using linked clinical and health administrative databases. Ontario is Canada's most populous province with nearly 14 million residents. All residents of Ontario have universal access to hospital care and medically necessary physicians' services, and those aged ≥ 65 years of age are provided universal prescription drug insurance coverage. The administrative data sets used in this study were linked using encoded identifiers at the patient level and analyzed at ICES. These data sets are routinely used to conduct studies involving palliative care (Data S1).^{28–32} The use of data in this project was authorized under Section 45 of Ontario's Personal Health Information Protection Act and was approved through a privacy impact assessment process that does not require review by a Research Ethics Board.

Study Cohort

Our cohort included Ontario adults with an existing diagnosis of HF who were in their last 2 years of life and died between January 1, 2010 and December 31, 2015. A diagnosis of HF was identified by the presence of 1 hospital record or physician claim, followed by a second record from either source within 1 year. This method has been previously validated with a sensitivity of 84.8% and a specificity of 97.0%.³³ We only included patients whose HF diagnosis was made ≥ 2 years before death because we are unable to measure the severity of heart failure using administrative data. We were specifically interested in end-of-life care as it related to people with chronic advanced HF and not, for example, end-of-life care for people with metastatic cancer who subsequently developed new acute HF in close proximity to death. Our study's index date (ie, the start of the observation period for our primary exposure) was, therefore, 2 years before the date of death.

People who were admitted to a nursing home in the last 2 years of life were excluded because the delivery of palliative care in this setting is not well captured using administrative data, and because the level of care in nursing homes typically allows people to die there.²⁹ The exclusion of people residing in this care setting may influence the absolute number of patients who receive palliative care based on our method of capturing its delivery. We also excluded people who received consultation with palliative care before the index date using a 5-year lookback to determine prior exposure. This “new-user” design is similar to pharmacoepidemiology studies and minimizes bias by restricting analysis to people who are initiating treatment when outcome risks are likely to vary over time.³⁴

Patient Characteristics

We measured demographic and clinical variables including duration of HF, comorbidities and chronic conditions,³⁵ use of acute healthcare services in the year before the study’s index date, cardiac-specific procedures in the 7 years before the index date, and, in the case of adults aged ≥ 66 years, the use of cardiovascular medications within 6 months of the index date. Cause of death was grouped according to a modified form of Becker leading cause of death.³⁶ We also determined the presence of functional decline in the year before the index date in a subset of adults who had completed homecare assessments (see Data S1 for details).

Receipt of Palliative Care

The main exposure was a person’s first encounter with palliative care in the last 2 years of life. We identified the delivery of palliative care based on a unique set of widely used physician claims fee codes.^{28–30,32,37–42} These codes were created to specifically indicate the delivery of palliative care by both generalist and specialist palliative care physicians and are related to therapies not intended to be curative, such as symptom management or counseling. Therefore, we captured a “palliative approach” to patient care and performed secondary analyses that measured potential differences between generalist and specialist palliative care. A physician was deemed to be a palliative care specialist based on a previously validated method with a sensitivity of 76.0% and specificity of 97.8%.³⁷ We measured the care setting and timing of initial consultation, the physician specialty for each palliative care encounter, the total number of palliative care encounters, as well as the models and setting of palliative care delivery.

We measured the delivery of 4 different models of physician palliative care delivery that were developed from an iterative process involving 8 healthcare providers

(physicians and nurses) with expertise in palliative care.³¹ These models are derived using the proportion of palliative care fee codes claimed by physicians, which classifies them as a palliative care specialist or palliative care generalist described above. The 4 models of palliative care were (1) no physician-based palliative care (0% of claims are palliative fee codes), (2) generalist palliative care (care is provided from either a primary-care physician or medical or surgical specialist such as an oncologist or general surgeon whose annual billing is comprised of $\leq 10\%$ of palliative care fee codes), (3) consultation palliative care (care provided by both palliative care specialists and generalists), and (4) specialist palliative care (a physician whose annual billing is comprised of $>10\%$ palliative care fee codes). The setting of palliative care was determined using physician claims, which included the locations in which care was delivered. There were 6 possible settings where palliative services could be delivered: inpatient, outpatient, home-based, multiple locations, third-party case management, and other (when the location is unknown). Third-party case-management fee codes were deemed to be a separate palliative care visit, even though they may be billed in conjunction with care delivered in other settings (Data S1).

Outcomes

The primary outcome was the location of death, which included hospital, home, or other. Deaths that occurred in a dedicated palliative care unit or hospice were categorized as other because there are very few palliative care units and hospices in Ontario.

Secondary outcomes included the number of hospitalizations and visits to the emergency department in the past 30, 90, and 360 days of life; the cumulative number of days spent in the hospital and in the emergency department in the past 30, 90, and 360 days of life; and the proportion of patients who underwent coronary artery bypass surgery, percutaneous coronary intervention, or newly implanted pacemakers or intracardiac defibrillators within the past 2 years of life. Incident use of these devices was determined using a 7-year lookback to ensure no prior device had been implanted.

Statistical Analyses

The association between receipt of newly initiated palliative care and the likelihood of death at home versus hospital was measured using multivariable multinomial logistic regression. The association between receipt of newly initiated palliative care and hospitalization in the last 30 days of life was measured using multivariable logistic regression. All models were adjusted for covariates with a standardized difference of ≥ 0.1 , which indicates imbalance among the study groups.⁴³

These variables included age, sex, rurality, neighborhood income, duration of HF, and the presence of metastatic cancer, dementia, diabetes mellitus, myocardial infarction, and stroke. We did not account for clustering by physician or facility because most people receive end-of-life care from many physicians in multiple facilities.

We performed a prespecified subgroup analysis in all adults who had received at least 1 palliative care visit to describe the model-specific factors of palliative care delivery associated with dying at home using multivariable multinomial logistic regression. We used a chi-squared test to compare categorical variables describing models of palliative care between death at home and death in hospital. We stratified the intensity of palliative care as ≤ 4 or > 4 visits because 58.4% of patients in our cohort had ≤ 4 palliative care visits. We stratified the timing from initial palliative care consultation until death based on previously recognized time frames: (1) "Optimal," between 2 years and 6 months before death; (2) "Appropriate," between 6 months and 30 days before death; and (3) "Late," < 30 days before death.⁴⁴

Because populations are aging and the burden of HF in the elderly is growing, we performed 2 sensitivity analyses measuring the association between palliative care and location of death in an additional 10 065 and 15 194 people with a more recent diagnosis of heart failure of ≥ 1 year and ≥ 6 months before death, respectively.

All analyses were performed using SAS version 9.4 (SAS Institute, Cary, NC) and used a 2-sided type 1 error rate of 0.05 as the threshold for statistical significance.

Results

Baseline Characteristics

There were 116 780 adults with HF who died during the study period, and 36 798 subjects were excluded from the study because they were institutionalized in a nursing home during the study period, indicating the substantial care needs of these patients. The final cohort consisted of 74 986 people (Figure 1).

Subjects in the cohort were typically older men (median age 78 years) with multiple cardiovascular risk factors who had had HF for a median of 7 years. The majority were prescribed HF-related therapies including diuretics.^{12,45} Cardiovascular disease was the leading cause of death, followed by cancer and respiratory disease (Table 1).

Receipt of Palliative Care, Death at Home, and Healthcare Use

There were 35 292 (47.1%) people who received at least 1 palliative care visit in the 2 years preceding death. Although

the baseline characteristics were similar between the 2 groups, those who received palliative care were slightly older and more likely to be female and to have comorbid cancer (Table 1).

Overall, 75.4% of patients died in a hospital. The proportion of people who received palliative care and died at home was more than twice that of those who did not receive palliative care (23.0% versus 10.7%). Palliative care was associated with a more than 2-fold likelihood of dying at home than in a hospital, compared with those who did not receive palliative care (adjusted odds ratio 2.12 [95% CI, 2.03–2.20]; $P < 0.01$) (Table 2). The magnitude of the association was larger in those with a more recent diagnosis of heart failure of ≥ 1 year and ≥ 6 months before death (adjusted odds ratio 3.06 [95% CI, 2.93–3.2] and 2.91 [95% CI, 2.79–3.04], respectively). We also found that being female (adjusted odds ratio 1.11 [95% CI, 1.06–1.15]; $P < 0.01$), having metastatic cancer (adjusted odds ratio 1.68 [95% CI 1.44–1.95]; $P < 0.01$), and having dementia (adjusted odds ratio 1.37 [95% CI 1.25–1.51]; $P < 0.01$) all were associated with an increased likelihood of death at home.

Palliative care was also associated with increased odds of hospitalization and a larger number of days in hospital in the last 30, 90, and 360 days of life (Table S1). Fewer than 3% of all patients underwent invasive procedures or device implantation during the study period, but palliative care was associated with lower rates of these procedures compared with those who did not receive palliative care.

Delivery of Palliative Care

Among all patients who received palliative care, 64.6% received their first palliative care consultation outside of a hospital, and 53.4% received palliative care services across multiple care settings. Across all 4 models of palliative care delivery, generalist physicians had the highest frequency of palliative care claims, at least 1 encounter with 61.0% of subjects. The delivery of palliative care was led by family physicians who were nonspecialists in palliative care 45.2% of the time. A generalist palliative care model was the most common type used and was delivered to 55.1% of people (Table 3, Table S2).

Among those who had at least 1 palliative care encounter, consultation was most frequently initiated late in a person's course of disease, occurring ≤ 30 days before death in 45.2% of people receiving palliative care (Table 3). Furthermore, a larger number of patients who died in a hospital received late palliative care compared with those who died at home (49.9% versus 32.1%, respectively). The main hospital admission diagnoses by receipt of palliative care are presented in Tables S3 and S4.

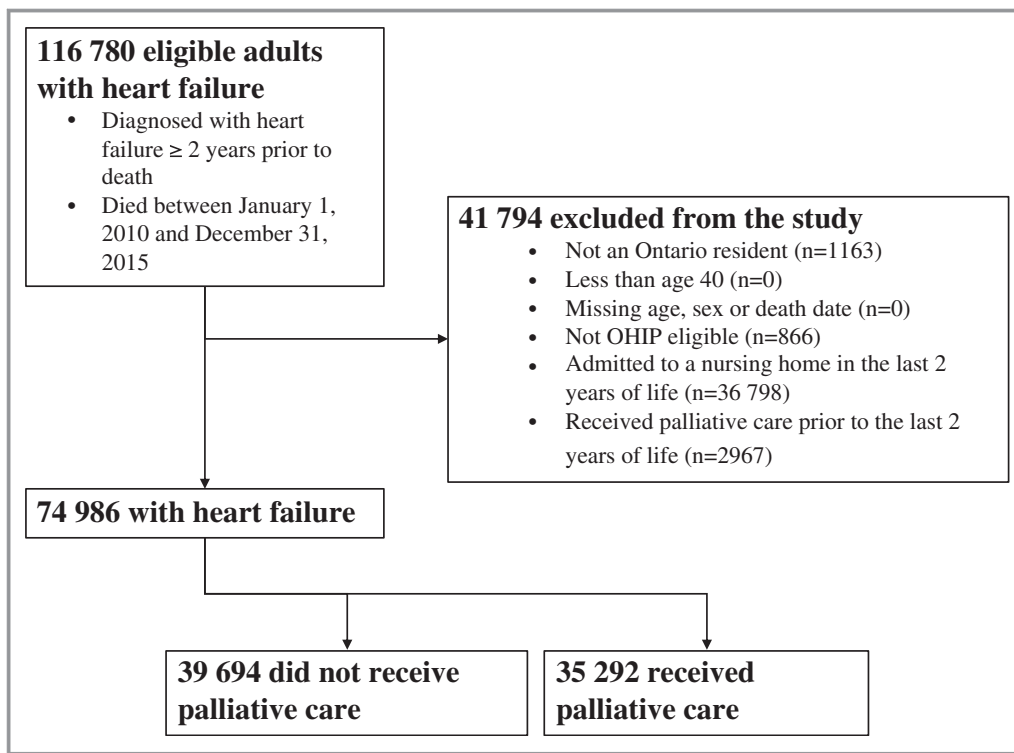


Figure 1. Flow diagram for the creation of the study sample. All adults with a diagnosis of heart failure made at least 2 years before their death were assessed for inclusion in the study. Patients who received their first consultation with palliative care and who did not reside in a nursing home at any point during the study period were included and subsequently divided into 2 groups: those who received palliative care and those who did not receive palliative care. OHIP indicates Ontario Health Insurance Plan.

There was a significant and positive association between patients who received home-based palliative care exclusively and death at home compared with those who received inpatient palliative care (Figure 2). Palliative care services that were delivered across multiple care settings were associated with increased odds of dying at home compared with those who received inpatient palliative care. Palliative care that was delivered as a consultative model involving a palliative care specialist compared with a generalist was also significantly associated with dying at home. Finally, receiving a higher intensity of palliative care, as reflected by having >4 visits, increased the odds of dying at home by more than 2-fold.

Discussion

Our cohort study of 74 986 community-dwelling adults who died with HF found that almost three quarters (75.4%) died in a hospital. Overall, 35 292 (47.1%) people received palliative care in the last 2 years of life, and palliative care was associated with a 2-fold increase in the odds of death at home compared with people who did not receive it. Among patients receiving palliative care, nonspecialist palliative care physicians led its delivery 61.0% of the time. A generalist model of

care was most often used (55.1% of patients), and palliative care was provided to 53.4% of patients in multiple locations. These findings support our hypothesis that palliative care in patients with HF is associated with death at home, a recognized indicator of high-quality end-of-life care.^{22,23}

Our findings have significant implications for the delivery of palliative care to people with noncancer illnesses such as HF. The proportion of adults dying with heart failure who receive palliative care is half of that for those dying with cancer (88%).³⁸ Prior research showed that 20% to 45% of patients died in an acute-care setting, a number that is substantially lower than the 75.4% of people in our study who died in a hospital with HF.^{28,46} These findings identify an opportunity to improve end-of-life care for patients with HF because most people report a preference for death at home.²¹

Our study demonstrated that the current models of palliative care being delivered are associated with an increased likelihood of death at home when patients receive it. As populations age and care becomes increasingly complex due to rising rates of multimorbidity,⁴⁷ continued investments in the training of both palliative generalists and specialists, along with expansion of home-based palliative care, will be needed to help people die at home.²⁸

Table 1. Characteristics by Receipt of Palliative Care of Adults Dying With Heart Failure in Ontario Between 2010 and 2015

	Receipt of Palliative Care		Weighted Standardized Difference*
	No (N=39 694)	Yes (N=35 292)	
Age, median (IQR), y	79 (71–86)	82 (75–87)	0.25
Female sex, n (%)	16 999 (42.8)	17 092 (48.4)	0.11
Duration of heart failure, median (IQR), y	7.1 (4.2–11.5)	7.1 (4.1–11.6)	0
Functional decline, n (%) [†]	5284 (13.3)	6117 (17.3)	0.11
Chronic conditions, n (%)			
Arrhythmia	18 755 (47.2)	17 221 (48.8)	0.03
Chronic kidney disease	6106 (15.4)	5083 (14.4)	0.03
Diabetes mellitus	12 753 (32.1)	10 235 (29.0)	0.07
Hypertension	35 508 (89.5)	31 748 (90.0)	0.02
Coronary artery disease	28 296 (71.3)	24 638 (69.8%)	0.03
Previous myocardial infarction	8229 (20.7)	6437 (18.2)	0.06
Stroke	3145 (7.9)	3101 (8.8)	0.03
Primary cancer	2209 (5.6)	2937 (8.3)	0.11
Metastatic cancer	269 (0.7)	669 (1.9)	0.11
Chronic obstructive pulmonary disease	8513 (21.4)	7218 (20.5)	0.02
Dementia	1215 (3.1)	1497 (4.2)	0.06
Depression/anxiety	5228 (13.2)	5215 (14.8)	0.05
Cardiovascular medications			
Antiplatelet	6573 (16.6)	5867 (16.6)	0
Anticoagulant	11 917 (30.0)	11 362 (32.2)	0.05
ACEi/ARB	24 203 (61.0)	22 098 (62.6)	0.03
β blocker	20 255 (51.0)	18 543 (52.5)	0.03
MRA	4542 (11.4)	4047 (11.5)	0
Furosemide	21 292 (53.6)	19 651 (55.7)	0.04
Digoxin	6316 (15.9)	5874 (16.6)	0.02
Metolazone	963 (2.4)	899 (2.5)	0.01
Cardiovascular devices/procedures [‡]			
CABG	614 (1.5)	471 (1.3%)	0.02
PCI	750 (1.9)	563 (1.6%)	0.02
Pacemaker	612 (1.5)	593 (1.7%)	0.02
ICD	328 (0.8)	228 (0.6%)	0.02
Cause of death, n (%)			
Cardiovascular disease	19 721 (49.7)	11 684 (33.1)	...
Cancer	2623 (6.6)	10 233 (29.0)	...
Sepsis	688 (1.7)	397 (1.1)	...
Diabetes mellitus	1956 (4.9)	1085 (3.1)	...
Dementia	640 (1.6)	1186 (3.4)	...
Falls	1102 (2.8)	822 (2.3)	...
Respiratory diseases	5373 (13.5)	4053 (11.5)	...
Gastrointestinal diseases	1929 (4.9)	1259 (3.6)	...

Continued

Table 1. Continued

	Receipt of Palliative Care		Weighted Standardized Difference*
	No (N=39 694)	Yes (N=35 292)	
Genitourinary diseases	1726 (4.3)	1691 (4.8)	...
All other causes	3936 (9.9)	1882 (5.3)	...

ACEi indicates angiotensin-converting enzyme inhibitor; ARB, angiotensin receptor blocker; CABG, coronary artery bypass graft; ICD, implanted cardioverter-defibrillator; IQR, interquartile range; MRA, mineralocorticoid receptor antagonist; PCI, percutaneous coronary intervention.

*Weighted standardized differences compare baseline characteristics of the study groups. A standardized difference less than 0.1 indicates good balance between the study groups for a given covariate.⁴³

[†]For people with a completed homecare assessment within the last 2 years of life. Functional decline was defined as patients who required a new homecare assessment in the 1 year before the index date or as a 1-point increase on their activities of daily living scale from prior homecare assessments.

[‡]A 7-year lookback was used to determine the prior presence of these devices and procedures.

Several prior studies reported similar findings to ours. In a recent systematic review measuring the effect of palliative care interventions on adults with HF, receipt of palliative care was significantly associated with death at home in 2 of the 4 studies that measured this outcome.¹⁸ Only 1 of the studies included in the systematic review was a randomized control trial, and it found a similar magnitude to our study in the likelihood of death at home (odds ratio 2.20 [95% CI, 1.3–3.7]). Of the remaining 3 lower-quality studies, 1 did not examine home deaths,⁴⁸ 1 was underpowered to detect a difference,⁴⁹ and the other study was a nonrandomized pilot study that demonstrated a trend toward increased likelihood of death at home but was limited in its conclusions by its study design.⁵⁰ Our study provides further evidence to support the association between palliative care and death at home in general, and specifically for patients with heart failure.

The limitations of our study are the lack of information on patient and caregiver preferences for location of death, their willingness to engage with palliative care, and on their overall goals of care and advance care plans. Furthermore, some patients may not be able to die at home (despite their preferences) because their symptoms are too complex for home-based management. We measured a “palliative approach” to care that includes both generalist and specialist palliative care physicians, which may underestimate the

magnitude of our findings given that we found an associated increased likelihood of death at home with specialist palliative care in a subgroup analysis comparing the 2 different models. In other jurisdictions effective specialist palliative care may be delivered by other types of clinicians such as nurse practitioners,⁵¹ which has important implications for its scalability. Our results may also be underestimated due to misclassification bias if physicians are providing palliative care but are not using palliative care fee codes. We also captured palliative care using fee codes in administrative data, a strategy that has been less successful in health systems without universal coverage.⁵² Our study setting also lacks robust hospice networks like those found in many areas of the United States, which may limit the ability of patients with significant care needs to die outside of the hospital setting unless they are admitted to a nursing home.²⁹ Our study excluded a large number of people admitted to nursing homes, which may partially account for the larger number of deaths in hospital when compared with other studies where 10% of people died in a nursing home.⁵³ Compared with other developed countries, Canada has been found to deliver hospital-centric end-of-life care, with over 50% dying in hospital compared with fewer than 30% in the United States.⁵⁴ Therefore, its generalizability to other jurisdictions requires confirmation. We also intentionally studied the population of patients with chronic heart failure and found similar results when we

Table 2. Association Between Receipt of Palliative Care and Location of Death, Hospitalization, or Emergency Department Visits in Adults Dying With Heart Failure in Ontario Between 2010 and 2015

	Unadjusted Odds Ratio (95% CI)	Adjusted* Odds Ratio (95% CI)
Death at home (vs hospital)	2.22 (2.13–2.32)	2.12 (2.03–2.20) [†]
Hospitalization in the last 30 days of life	1.26 (1.22–1.3)	1.27 (1.23–1.31) [†]
Emergency department visit [‡] in the last 30 days of life	0.76 (0.73–0.78)	0.77 (0.74–0.79) [†]

*Models were adjusted for age, sex, rurality, neighborhood income, duration of heart failure, and the presence of metastatic cancer, dementia, diabetes mellitus, myocardial infarction, and stroke.

[†]P<0.01.

[‡]Emergency department visits not resulting in hospital admission.

Table 3. Description of the Delivery of Palliative Care in Adults Dying With Heart Failure in Ontario Between 2010 and 2015

	Location of Death			All Patients Receiving Palliative Care n=35 292	P Value*
	Home n=8109 (23.0%)	Hospital n=25 991 (73.6%)	Other n=1192 (3.4%)		
Location of initial palliative care consultation, n (%)					
Inpatient	615 (7.6)	3749 (14.4)	72 (6.0)	4436 (12.6)	<0.01
Outpatient	2316 (28.6)	11 160 (42.9)	434 (36.4)	13 910 (39.4)	...
Home-based	3050 (37.6)	5405 (20.8)	434 (36.4)	8889 (25.2)	...
Subacute care [†]	10 to 16 (0.1 to 0.2) [‡]	300 to 326 (1.2 to 1.3) [‡]	4 to 10 (0.3 to 0.8) [‡]	333 (0.9)	...
Third party [†]	2111 (26.0)	5350 (20.6)	243 (20.4)	7704 (21.8)	...
Other	0 to 6 (0.0 to 0.1) [‡]	0 to 6 (0.0 to 0.0) [‡]	0 to 6 (0.0 to 0.5) [‡]	0 to 6 (0.0 to 0.0) [‡]	...
Locations of all Palliative Care Provided, n (%)					
Inpatient	74 (0.9)	1532 (5.9)	8 (0.7)	1614 (4.6)	<0.01
Outpatient	621 (7.7)	6764 (26.0)	229 (19.2)	7614 (21.6)	...
Home-based	1915 (23.6)	3179 (12.2)	356 (29.9)	5450 (15.4)	...
Multiple locations	5212 (64.3)	13 117 (50.5)	531 (44.5)	18 860 (53.4)	...
Third party	279 (3.4)	1197 (4.6)	61 (5.1)	1537 (4.4)	...
Other	8 (0.1)	202 (0.7)	7 (0.6)	227 (0.6)	...
Model of palliative care , n (%)					
Generalist only	4007 (49.4)	14 743 (56.7)	710 (59.6)	19 460 (55.1)	<0.01
Consultative	2486 (30.7)	5955 (22.9)	256 (21.5)	8697 (24.6)	...
Specialist only	1616 (19.9)	5293 (20.4)	226 (19.0)	7135 (20.2)	...
Number of palliative care visits, n (%)					
1 to 4	3623 (44.7)	16 278 (62.6)	718 (60.2)	20 619 (58.4)	<0.01
5 to 9	1552 (19.1)	4043 (15.6)	171 (14.3)	5766 (16.3)	...
10 to 14	845 (10.4)	1695 (6.5)	67 (5.6)	2607 (7.4)	...
15+	2089 (25.8)	3975 (15.3)	236 (19.8)	6300 (17.9)	...
Timing of initial palliative care consultation [¶] , n (%)					
Optimal	1884 (23.2)	4287 (16.5)	296 (24.8)	6467 (18.3)	<0.01
Appropriate	3626 (44.7)	8732 (33.6)	502 (42.1)	12 860 (36.4)	...
Late	2599 (32.1)	12 972 (49.9)	394 (33.1)	15 965 (45.2)	...

*A chi-squared test was used to compare categorical variables describing models of palliative care between death at home vs death in hospital.

[†]Subacute care includes both nursing homes and complex continuing-care units. Third-party care typically includes telephone support, weekly case management, and outpatient case conference. See Data S1 for details.

[‡]Data presented as ranges of values in accordance with ICES privacy policy to prevent a disclosure of a cell size containing 5 or fewer subjects.

^{||}The 4 models of palliative care were (1) no physician-based palliative care, (2) generalist palliative care (eg, from a primary-care physician or medical specialists such as internists and oncologists), (3) consultation palliative care (ie, care from both palliative care specialists and generalists), and (4) specialist palliative care.³¹

[¶]Timing is measured in terms of proximity to death (ie, the number of days from initial visit until death): optimal, between 2 years and 6 months before death; appropriate, between 6 months and 30 days before death; late, less than 30 days before death.

included those with a more recent diagnosis of HF. However, we were unable to determine if they had preserved or reduced ejection fraction. Therefore, potential differences in our findings that are related to the classification of HF remain unknown. We suspect that the higher numbers of hospitalizations and days spent in the hospital in the last year of life among people receiving palliative care are related to the

severity of their illness and increased care needs, which are not readily measured in administrative data. Late referral to palliative care may come as a consequence of hospitalization events that occur near death and trigger care teams to refer, although this is not wholly explained because nearly 65% of subjects in our study had their first consultation with palliative care outside the hospital setting.

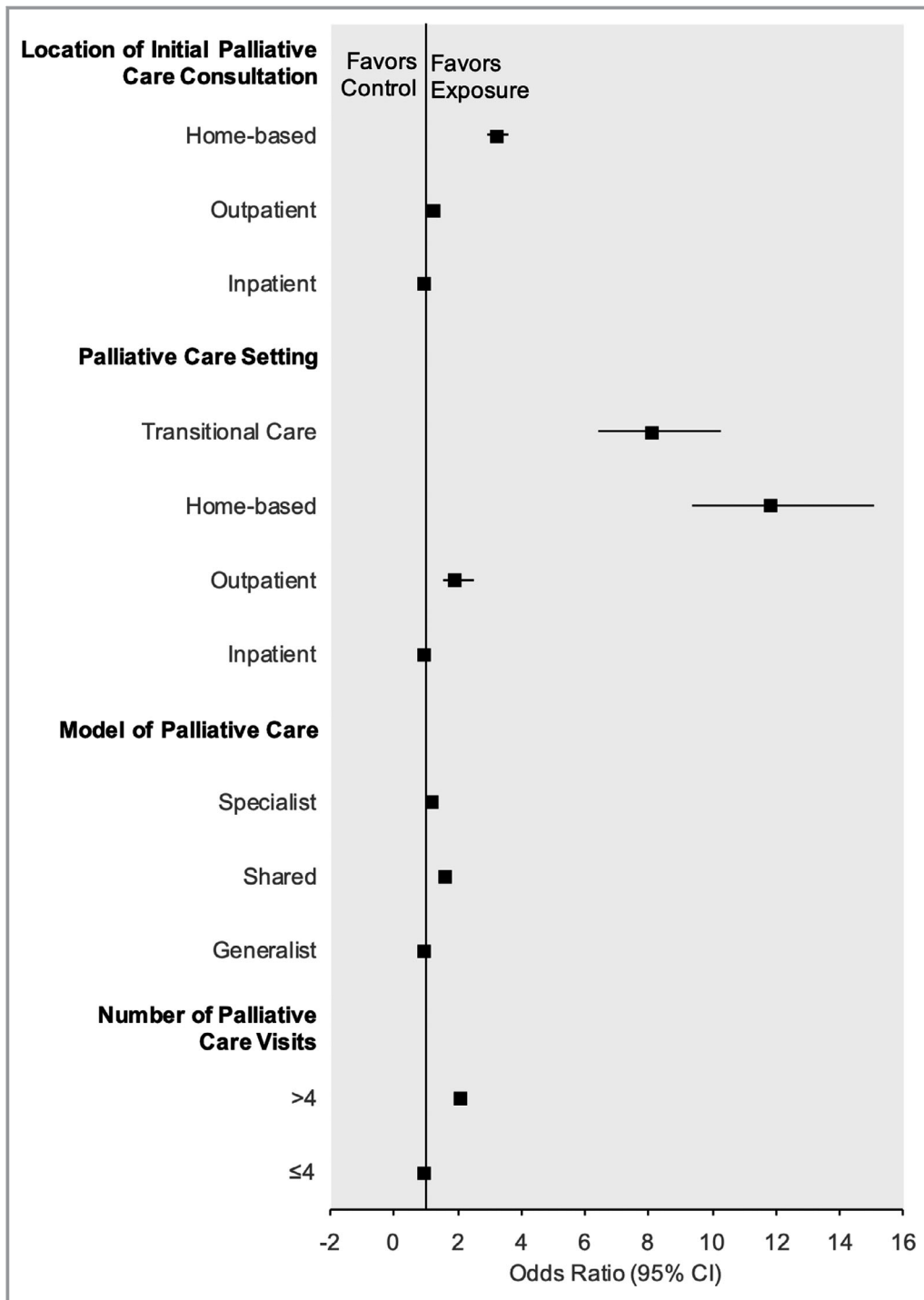


Figure 2. Subgroup analysis of components of palliative care delivery and death at home. Association between delivery of different components of palliative care services and death at home (vs death in hospital) among adults dying with heart failure in Ontario between 2010 and 2015 who received palliative care. Models were adjusted for age, sex, rurality, neighborhood income, duration of heart failure, and the presence of metastatic cancer, dementia, diabetes mellitus, myocardial infarction, and stroke.

Significant questions remain about which models of palliative care and the timing of its initiation will have important effects on patient- and policy-oriented outcomes.⁵⁵ Prior work reported a 45% relative reduction in the number of

hospital admissions at 12 weeks of follow-up using a transitional home-based palliative care model compared with usual care.⁵⁶ In a randomized trial comparing inpatient palliative care to usual care, there was no reduction in

readmission to hospital at 30 days.⁵⁷ Future work will need to evaluate in more detail the effects of timing and different models of palliative care on place of death and healthcare use and take into consideration the potential impact of cultural and racial differences between patients on preferences for these outcomes.⁵⁸

Conclusions

Most people with HF die in a hospital and do not receive palliative care. Providing palliative care near the end of life was associated with an increased likelihood of dying at home. These findings suggest that scaling existing palliative care programs to increase access may improve end-of-life care in people dying with chronic noncancer illness.

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Disclosures

None.

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SUPPLEMENTAL MATERIAL

Data S1.

Association Between Palliative Care and Death at Home in Adults with Heart Failure

Description of datasets

The following datasets were used: 1) the Registered Persons Database is a registry of all Ontarians eligible to receive insured health services in the province and contains detailed demographic information as well as the Local Health Integration Networks (LHIN), which defines Ontario 14 regional areas within which people received most of their hospital care from local hospitals; 2) the Ontario Drug Benefit (ODB) database provides individual prescription records including all prescriptions dispensed to Ontario residents aged 65 years and older;; 4) the Ontario Health Insurance Plan (OHIP) database identified physician billing claims and specialty; 5) the Canadian Institute for Health Information Discharge Abstract Database (CIHI-DAD) contains detailed diagnostic and procedural information for all hospital admissions in Canada;¹ 6) the National Ambulatory Care Reporting System (NACRS) database reports demographic, administrative, clinical and service-specific data for Emergency Department visits; 7) the Continuing Care Reporting System (CCRS) database contains demographic, administrative, clinical and resource utilization information on patients who receive continuing care services in hospitals or long-term care (LTC) homes in Canada. The long-term care dataset is generated from the Individual Assessment Instrument Minimum Data Set 2.0, a mandatory comprehensive, standardized instrument for evaluating the needs, strengths, and preferences of elderly adults residing in nursing homes and receiving home care, contains detailed information on the functional status of these people. Full assessments are completed on admission or referral, at quarterly intervals and following any significant health status change;² 8) the Ontario Mental Health Reporting System (OMHRS) database documents admissions to designated psychiatric

beds; 9) the Ontario Congestive Heart Failure (CHF) database contains all Ontario individuals with CHF identified since 1991; 10) the National Rehabilitation Reporting System (NRS) contains patient data collected from participating adult inpatient rehabilitation facilities and programs across Canada; 11) The Same Day Surgery (SDS) data sets contains patient-level data for day surgery institutions in Ontario. Every record corresponds to one same-day surgery or procedure stay; 12) the Home Care Database (HCD) contains patient-level data on government-funded home and community services.

Determining the presence of heart failure

A diagnosis of heart failure (HF) is identified using ICD-10 codes I500, I501 and I509.

A person is said to have heart failure (HF) if s/he had one hospital admission (either from the DAD or from OMHRS) with a HF diagnosis or an OHIP claim/NACRS ED record with a HF diagnosis followed within one year by either a second record with a HF diagnosis from any source.

The above coding algorithm has a sensitivity of 84.8 (95% CI 77.7-92.0), a specificity of 97.0 (95% CI 96.3-97.9) and a positive predictive value of 55.6 (95% CI 47.6-63.6).³

Determining use of cardiac-specific procedures or devices

The following procedure codes were used from the Canadian Classification of Health Interventions:

- Pacemaker: 1HZ53GRNM, 1HZ53LANM, 1HZ53GRNK, 1HZ53LANK, 1HZ53GRNL, 1HZ53LANL
- Intracardiac Defibrillator: 1HZ53GRFS, 1HZ53LAFS, 1HZ53SYFS, 1HZ53HAFS
- Coronary Artery Bypass Grafting: 1IJ76
- Percutaneous Coronary Intervention: 1IJ50, 1IJ54, 1IJ57GQ

Physician claims fee codes used to identify delivery of palliative care including location

Outpatient

- A945 (without and with B codes): Special palliative care consultation in clinic, office, home; minimum 50 min
- K015 (if no other feecode combination below was met): Counselling of relatives on behalf of catastrophically or terminally ill patient

- K023 (if no other feecode combination below was met): Palliative care support in half hour increments; may be used to add time for longer consultations following a code for A945, or for any PC support visit. Exclude if patient is in hospital, long-term care (LTC), complex continuing care (CCC), or rehabilitation

Home-based

- A900 with (B966, B998, B997): Complex house call assessment
- A901 with (B966, B998, B997): House call assessment
- A945 with any B code: Special palliative care consultation
- K023 with A900 A901 or any B code: Palliative care support
- K015 with A900 A901 or any B code: Counselling of relatives on behalf of catastrophically or terminally ill patient
- B966: Palliative care home visit; travel premium – weekdays daytime
- B998 : Palliative care home visit; special visit premium – weekdays daytime, first person seen
- B997: Palliative care home visit; special visit premium – nights, first person seen
- A900 A901 B960 B961 B962 B963 B964 B986 B987 B988 B990 B992 B993 B994 B996 within the last 3 months prior to death

Hospital inpatient

- C945: Special palliative care consultation
- C882: Palliative care; Non-emergency subsequent visits by the MRP following transfer from an Intensive Care Area
- C982: Palliative care; Emergency subsequent visits by the MRP following transfer from an Intensive Care Area
- K015 with (C945 C882 C982): Counselling of relatives on behalf of catastrophically or terminally ill patient
- K023 with (C945 C882 C982): Palliative care support in half hour increments; may be used to add time for longer consultations following a code for A945, or for any PC support visit.

Subacute care

- W882: Palliative care; Long-term care subsequent visit
- W982: Palliative care; Long-term care subsequent visit (for community medicine practitioners)
- K015 with (W882 W982): Counselling of relatives on behalf of catastrophically or terminally ill patient
- K023 with (W882 W982): Palliative care support in half hour increments; may be used to add time for longer consultations following a code for A945, or for any PC support visit.

Third-party encounters

- G511: Telephone services to patient receiving PC at home (max. 2/week)
- G512: Weekly care case management from palliative primary care management (Monday–Sunday)
- K700: Palliative care outpatient case conference

Determining location of death by datasets

Hospital

- DAD
- NACRS
- OMHRS
- NRS
- SDS
- CCRS (Hospital)

Home

- HCD
- OHIP

Other

- CCRS (LTC)
- Unknown

Determining functional decline in people who have received a RAI assessment

‘Yes’ for any of the following conditions:

Use a 2-year lookback from index date to determine if an person has had a prior RAI completed

- New RAIHC assessment in the 1 year prior to index date*
- Increase in 1 point on activities of daily living scale (long form) from last assessment*
 - Must fall in the 1 year prior to index date*
- Increase in 1 point on activities of daily living scale (self-form) from last assessment*
 - Must fall in the 1 year prior to index date*
- Variable “ADL Decline” = “Yes” from last assessment*
 - Must fall in the 1 year prior to index date*

If any of ‘c’-‘e’ do not fall in the 1 year prior to index date, code this as “No” (i.e. this does not count as the presence of functional decline)

Table S1. Location of death, healthcare utilization and invasive cardiac procedures in patients dying with heart failure in Ontario between 2010 and 2015, by receipt of palliative care.

	Receipt of Palliative Care	
	No N=39,694	Yes N=35,292
Location of death, n (%)		
Hospital	30,561 (77.0)	25,991 (73.6)
Home	4,228 (10.7)	8,109 (23.0)
Other	4,905 (12.3)	1,192 (3.4)
Number of hospital admissions, median,(IQR)		
Last 360 days of life	1 (1-2)	2 (1-3)
Last 90 days of life	1 (1-1)	1 (1-2)
Last 30 days of life	1 (0-1)	1 (0-1)
Number of hospital days, median,(IQR)		
Last 360 days of life	12 (3-28)	21 (9-41)
Last 90 days of life	7 (1-19)	13 (4-27)
Last 30 days of life	5 (0-14)	8 (0-19)
Number of emergency department visits, median,(IQR)		
Last 360 days of life	1 (0-3)	1 (1-3)
Last 90 days of life	0 (0-1)	1 (0-1)
Last 30 days of life	0 (0-1)	0 (0-1)
New Devices/Procedures, n(%)		
CABG	71 (0.2%)	47 (0.1%)
PCI	750 (1.9%)	563 (1.6%)
PPM	269 (0.7%)	173 (0.5%)
ICD	84 (0.2%)	43 (0.1%)

IQR – Interquartile range, CABG – coronary artery bypass grafting, PCI – percutaneous coronary intervention, PPM – permanent pacemaker, ICD – intracardiac defibrillator

Table S2. Description of the physician mix in delivery of Palliative Care to patients dying with heart failure in Ontario between 2010 and 2015.

	Location of Death			All Patients Receiving Palliative Care n= 35,292
	Home n=8,109 (23.0%)	Hospital n=25,991 (73.6%)	Other n=1,192 (3.4%)	
Most Involved Palliative Care Physician Types, n,(%)				
<i>Palliative Care Specialist</i>				
General Practitioner	1,491 (18.4)	4,415 (17.0)	189 (15.9)	6,095 (17.3)
Specialist	125 (1.5)	878 (3.4)	37 (3.1)	1,040 (2.9)
<i>Palliative Care Generalist</i>				
General Practitioner	3,775 (46.6)	11,568 (44.5)	623 (52.3)	15,966 (45.2)
Specialist	232 (2.9)	3,175 (12.2)	87 (7.3)	3,494 (9.9)
<i>Shared Palliative Care</i>				
General Practitioner	643 (7.9)	1,087 (4.2)	50 (4.2)	1,780 (5.0)
Specialist	62 (0.8)	238 (0.9)	7 (0.6)	307 (0.9)
General Practitioner/Palliative Care Specialist	1,594 (19.7)	3,805 (14.6)	185 (15.5)	5,584 (15.8)
Specialist/Palliative Care Specialist	187 (2.3)	825 (3.2)	14 (1.2)	1,026 (2.9)

Table S3. Admission diagnoses by study group for first hospitalization in the last year of life.

	Receipt of Palliative Care	
	No N=39,694	Yes N=35,292
Admission Diagnosis, n (%)	Heart Failure 3,122 (6.6)	Heart Failure 2,368 (5.0)
	Sepsis 1,178 (2.5)	Sepsis 775 (1.6)
	COPD 1,077 (2.3)	Pneumonia 704 (1.5)
	Pneumonia 971 (2.1)	COPD 661 (1.4)
	NSTEMI 827 (1.8)	AKI 565 (1.2)

The 5 most frequent admission diagnoses for a patient's first hospitalization in the 6 months prior to death among community-dwelling adults dying with heart failure residing in Ontario between 2010 and 2015.

COPD – Chronic Obstructive Pulmonary Disease, NSTEMI – Non-ST Elevation Myocardial Infarction, AKI – Acute Kidney Injury

Table S4. Admission diagnoses by study group for hospitalizations in which patients died.

	Receipt of Palliative Care	
	No N=39,694	Yes N=35,292
Admission Diagnosis, n (%)	Heart Failure 4,514 (6.7)	Heart Failure 3,975 (5.9)
	COPD 2,631 (3.9)	Pneumonia 1,264 (1.9)
	NSTEMI 1,319 (2.0)	COPD 1,135 (1.7)
	Pneumonia 1,245 (1.9)	COPD 1,064 (1.6)
	AKI 704 (1.0)	NSTEMI 876 (1.3)

The 5 most frequent admission diagnoses among patients who died in hospital among community-dwelling adults dying with heart failure residing in Ontario between 2010 and 2015.

COPD – Chronic Obstructive Pulmonary Disease, NSTEMI – Non-ST Elevation Myocardial Infarction, AKI – Acute Kidney Injury

Supplemental References:

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